Everyday Occupation, Well-Being, and Identity: The Experience of Caregivers in Families With Dementia

Betty R. Hasselkus, Bridget J. Murray

The purpose of this study was to gain understanding of the nature of the daily occupations of caregivers for family members with dementia as related to the caregivers’ perceptions of well-being. Qualitative telephone interviews, focused on the experience of caregiving, were conducted with 33 caregiver–respondents; the data were transcribed and analyzed using a phenomenological approach. Everyday occupation emerged as a phenomenon that was central to the caregivers’ ways of evaluating and monitoring well-being in the care receivers and themselves. Further, occupational engagement served to help mitigate the potential biographical disruption of the dementia caregiving experience. The implications for occupational therapy personnel are convincing: Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.


There’s no vocabulary
For love within a family…

The majority of care for people with Alzheimer’s disease and related dementias is carried out in the community by family and friends (National Academy on an Aging Society, 2000). The effect of such care on the occupational contexts of caregivers’ lives is well supported and has been described as leading to “drastic life-style changes” (Wilson, 1989, p. 95). In a study by Ory, Hoffman, Yee, Tennesstedt, and Schultz (1999), more than half of the caregivers for persons with dementia had taken time off from work, given up leisure activities, and had less time to spend with other family members because of the caregiving responsibilities. Loos and Bowd (1997) reported themes of loss of employment and loss of social and recreational interaction in their caregiver interviews, and Globerman (1997) and Wilson (1989) reported suspension of developmental tasks such as dating and doing volunteer work.

Not all influences on the dementia caregivers’ occupational experiences are characterized as loss or giving up. Beach (1997) reported a major theme of increased sibling activity and sharing among her sample of adolescents in caregiving families; siblings who lived away from home returned for visits more frequently than previously, and special activities and outings often were planned for diversion and caregiving respite. In her autoethnographic account of caregiving for her father throughout his dementia, Thibeault (1997) described the new openness and deep sharing that developed between her and her father as they read books on spirituality together; “... for the first time since I have been out of diapers, my father hugged me” (p. 113).

The dementia caregiving experience itself often is described in occupational terms, for example, as a domain of day-to-day management requiring the caregiver to develop strategies for decision making, problem solving, and conflict management (Corcoran, 1994; Corcoran & Gitlin, 1992; Willoughby & Keating,
In addition to occupational implications, phenomenological research on dementia caregiving has raised issues related to the caregiver’s sense of self and identity as embedded in the care provision context. Identity is the meaning a person attributes to the self (Burke, 1980); further, identity is “relational, social, placed in a context of interaction” (p. 18). Changes in relationships between caregivers and family members with dementia are characterized as leading to a process of “becoming strangers” (Wuest, Ericson, & Stern, 1994, p. 437); caregivers and care receivers are described as experiencing a progressive sense of asynchrony, loss of mutuality, personal disconnection, and detachment from each other (Jones & Martinson, 1992; Lynch-Sauer, 1990).

The bulk of identity research in the context of dementia has focused on the person receiving care, not on the person providing care (Cohen-Mansfield, Golander, & Arnhem, 2000; Herskovits, 1995; Jenkins & Price, 1996; Sabat & Harré, 1992). In one exception, Orono (1990) described three primary aspects of the interactions between a caregiver and a family member with dementia that are markedly altered as the disease progresses: reciprocity, social structure, and temporality. One member of the dyad (the person with dementia) does not continue to interact with the other (the caregiver) as expected; as a result, the caregiver gradually becomes aware that he or she is losing prior habitual patterns of interaction and part of a previously shared biographical history. The caregivers’ efforts to “normalize” the situation include what Orono describes as “memory keeping” (p. 1254) — reenactments of everyday activities that were part of the shared history before the dementia. Gradually, over time, the caregivers in her study “lost remnants of their own identity” (p. 1255); “As the person’s [caregiver’s] extant world view is shattered, what is called for is a different perspective and meaning to life’s past events or beliefs as well as new parameters to identity” (p. 1253).

Thus, two major themes of meaning emerge in the experience of caregiving for a family member with dementia: occupation and identity. In occupational therapy literature, Christiansen (1999) has proposed theoretical links between occupation and identity, stating that “occupations constitute the mechanism that enables persons to develop and express their identities” (p. 556). Dickie (2003) examined the complexity of worker identities among home crafters. Others have focused on the relationship of creative occupations to the development of the self (Howie, Coulter, & Feldman, 2004; Reynolds, 2003), the identity work embedded in holiday food occupations (Wright-St. Clair, Hocking, Bunrayong, Vittayakorn, & Rattakorn, 2005), and occupational identity in relationship to health and illness (Braveman & Helfrich, 2001; Charmaz, 2002; Christiansen, 2000; Liberté-Rudman, 2002; Nygård & Borell, 1998; Purves & Suto, 2004). All have offered support for the importance of daily occupation in the construction and reconstruction of the self throughout the lifetime. The literature of occupational therapy, however, resembles that from outside the field in that the emphasis has not been on shared identities, such as those found within the family caregiving context. The meanings of occupation in caregiving generally (Hasselkus, 1989) and, more specifically, in dementia caregiving (Hasselkus, 1992a, 1998) also have been the objects of research, but these studies do not all focus on family caregivers, nor do they specifically address identity and occupation.

This study addresses the phenomenon of everyday caregiving as experienced by caregivers for family members with dementia. The purpose of this analysis is to gain understanding of the nature of the caregivers’ daily occupations as they relate to the caregiver’s perceptions of well-being and, by implication, to enable occupational therapists to work together more effectively with family caregivers—assisting them both to carry out the occupational demands of the caregiving responsibilities and to tailor their occupations in such a way that their lives retain a sense of “life unity and purpose” (McAdams, 1997, p. 61).

Method

This study is based on two assumptions: (a) narratives are a salient source for understanding the nature of an experience, and (b) meanings associated with the dementia caregiving experience are interpretable through narratives about people’s biographical contexts, their routines of everyday life, and their social interactions (Becker, 1994; Bruner, 1990; Coles, 1989; Mattingly, 1998; Polkinghorne, 1988; Riessman, 1990). Riessman defined narrative as discourse that is “organized around time and consequential events in a ‘world’ recreated by the narrator” (p. 1195); she stated that narrative is a research method that is “particularly well suited to studying the presentation of self in everyday life” (p. 1195). In the current study, we used telephone interviews to elicit narratives of especially satisfying and dissatisfying experiences of care from family caregivers. In the analysis of the narratives, we aimed to understand the phenomenology of everyday occupation as it was lived by the family caregiver-respondents. McAdams’s (1990) life story model of identity further informed the analysis of the narratives.
Participants

The South-Central Wisconsin Chapter of the Alzheimer’s Association sent recruitment letters for the study to a confidential list (randomly generated) of 250 family caregivers from its master list. The letters contained return postcards addressed to the principal investigator (the first author). The agency sent out all 250 letters over an 8-month period. At the end of the mailing, 32 postcards had been returned, of which 27 resulted in interviewees (4 returnees were not caregivers, 1 stated she did not wish to participate). During the subsequent 2 months, the agency staff attempted to contact a portion of the nonrespondents on the list by telephone; this effort resulted in 6 more participants, bringing the total number of caregivers in the study to 33. In phenomenological research, a sample of from 6 to 8 respondents is deemed adequate for a homogeneous sample and from 12 to 20 respondents for ensuring maximum variation and discovery of disconfirming data (Kuzel, 1992; McCracken, 1988).

Of the 33 caregiver–respondents in the study, 27 were women (ages 34–82, mean age 56) and 6 were men (ages 33–81, mean age 58). Seventeen of the female caregivers were daughters, 3 were daughters-in-law, and 7 were wives; four of the male caregivers were sons and 2 were husbands. No information on racial or ethnic group was obtained. Fourteen (51%) of the women lived with their care receivers, as did 3 (50%) of the men. Seventeen of the caregivers had used day-care services, and 11 had in-home help; other services such as sitters, home-delivered meals, respite care, and help with yard work were used by up to 3 caregivers. Approval of the appropriate university human subjects committee for the study was received, and verbal informed consent was recorded at the beginning of each taped telephone interview.

The Interview Process

A graduate research assistant carried out in-depth telephone interviews with all 33 respondents, following an interview method used in an earlier study (Hasselskus & Dickie, 1994). The interviews were phenomenological (Van Manen, 2003), with the interviewer simply explaining that we were interested in gaining an understanding of the caregiver’s experience in providing care for his or her family member and asking the caregiver to begin by telling us about a very satisfying experience. (Later in the study process we decided to ask first about a very dissatisfying experience to end the interview on a more positive note with a satisfying experience.) In each interview, the graduate assistant used verbal probes in response to the emerging narrative to encourage the caregiver to provide as much detail and context as possible. The probes also served the purpose of keeping the caregiver in the story, maximizing the possibility of staying close to the actual lived experience, and helping to avoid interpretive thoughts about the experience (Van Manen, 2003). Interviews were, on average, about 35–45 minutes in length; each interview was audiotaped and transcribed verbatim.

The graduate assistant and I (first author) completed an initial level of analysis on the early interviews, first independent of each other and then together to reach consensus on tentative emerging themes of meaning. On the basis of the meanings on which we agreed, I planned and conducted callback interviews with 8 of the 33 respondents. The callback interviews offered opportunities for member checks on our initial tentative interpretations and themes and a chance for the respondents to clarify and elaborate further on their earlier responses.

The Analysis

Narrative has been described as “an essential means by which persons make sense of their experience” (Brock, 1995, p. 152). To the researcher, narratives offer a degree of access to the meanings that organize a person’s daily actions and events. We fully recognize that stories relayed by respondents provide interpretative accounts of prior experiences and that these interpretations give us guidelines for our own interpretations of the experiences. As researchers in this study, our own interpretations are influenced by the fact that we are occupational therapists and, as such, we tend to see the people with whom we interact within an occupational framework. Taking this interpretive sequence one step further, Riessman (1990) has cautioned readers of narrative research to remain aware that they construct their own interpretation of the researcher’s interpretation of the respondent’s interpretation of his or her experiences.

When illness is present, a central task of narrative is to provide coherence to the resulting “confusions and chaos” in a person’s life (Mattingly, 1998, p. 107). Narratives in the study reported here are illness narratives; framed within narrative theory, they represent the caregiver’s presentation of the self in the context of caregiving for a person with dementia as well as his or her search for a sense of coherence and continuity amid the confusion and, sometimes, chaos of the caregiving phenomenon.

We began the analysis of the interviews with the very general question, “What all is here?” We started by identifying the types of occupation-related experiences that were in the narratives and then moving to identifying the themes within the experiences (Van Manen, 2003). For example, one type of experience we found early was that of “finding a place” (housing); one theme within this experience was
“finding a place that works” as a source of satisfaction and sense of well-being to the caregiver. In the callback interviews, early themes of experience were revisited to deepen understandings between researcher and respondent.

On the next level of analysis, we consolidated the themes across all interviews into 10 clusters or categories of occupational experience. At this stage in the analysis, the thread of a meaning structure related to “shared identity” emerged. “Finding a place that works” meant more than finding a place for the care receiver that would support his or her well-beings; it also meant finding a place that supported who the care receiver had been “before” and, thus, who the caregiver had been “before.” When the caregiver described how she finally found a group home where her mother “was kept active . . . my mother always loved knitting and doing crafts work . . . they had music, and she loved singing,” the daughter was, on one level of analysis, describing a place of occupational well-being for her mother. But to us, pushing the analysis further, seeing her mother doing things she had “always loved” was an expression of the daughter’s sense of having her mother “back” again in some ways, and having her mother “back” meant also reclaiming a portion of her own lifelong personhood and identity as shared with her mother.

With the concept of shared identity as an overlay, the 10 occupational themes of experience were further synthesized into three primary themes of everyday occupation: 1. Everyday occupation as a representation (to the caregiver) of the care receiver’s state of being (well-being, lack of well-being, good day/bad day, doing poorly, getting “worse”); 2. Everyday occupation as a reflection of the caregiver’s state of being (own well-being or lack of well-being, disrupted daily life, loss of taken-for-granted world); and 3. Everyday occupation as a means for the caregiver to seek and maintain relationship with the care receiver and the larger community of family, neighbors, and health professionals (to manage care receiver behaviors, create well-being, recover or maintain some sense of continuity of family history and relationships).

Disruptions of the caregiver’s identity and sense of unity of life are embedded in the narratives of everyday occupation; occupational engagement helps the caregiver meet the challenges and live through the biographical disruption that accompanies the dementia caregiving experience.

Everyday Occupation: The Fabric of Well-Being

Everyday occupation can be thought of as the fabric of well-being in the dementia caregiving experience. The three primary themes of meaning of occupation in dementia caregiving yield understandings of everyday occupation as a phenomenon through which challenges to the well-being of the care receiver and the caregiver are revealed and from which strategies to meet these challenges are generated. (Author’s Note: In the following paragraphs, minor changes have been made in a few verbatim quotations to ensure confidentiality of respondents.)

**Theme 1: The Care Receiver’s State of Being**

Last year for Thanksgiving, my father hadn’t been eating, and we went to pick him up [at the nursing home] and brought him to my house for Thanksgiving dinner. My father had always loved prime rib, so I had fixed prime rib for Thanksgiving dinner. I had turkey and everything, but I also had prime rib. When I fixed my father’s plate, I said, “Dad, this is prime rib,” and I put a piece in his mouth. My father tasted it, and for some reason, he just started grabbing, reaching for the plate. I could not get it in him fast enough. He started chewing, and he hadn’t chewed in almost a month. That was the most [pause], it was the most uplifting . . . it was just a miracle, that’s about all I can say. That made Thanksgiving beautiful.

Well-being. This caregiver’s story of Thanksgiving dinner with her father is an exemplar of a moment of well-being for the care receiver as perceived by the daughter. The moment of well-being is embedded in a context of marked lack of well-being—that is, the father is in deep dementia, is in a “geri” [geriatric] chair, is being fed—yet, within that context of impairment, the daughter perceived a moment of relative well-being in her father. The “moment” is without question memorable. And the moment is occupational.

Instances of well-being for the care receiver, as described in the experiences shared by the caregivers in this study, often were transitory and comprised moments during ordinary daily occupations. To rent a movie that was funny “for both of us,” to go to a restaurant that had “a particular dessert that he likes,” or to see her mother “smile, and lean forward” when the granddaughter came to see her—these were perceived by the caregivers as moments of well-being for the care receivers. For one daughter caregiver, “The best part was when I brought her down here to live with me, and I was able to take her and get her [hair fixed], and I’d get her all cleaned up, and she used to love to sit here in the living room and look out the front window. And if I’d go to the store or something, she’d be right here in the front window.” What was ordinary and taken-for-granted “before” became extraordinary and not taken-for-granted in the experience of dementia.

Lack of well-being. Lack of well-being, too, was described in occupational terms. The caregivers’ tales of the
care receivers’ ill-being ranged from highly charged experiences of the care receiver being lost in a store or neighborhood, or coming to the door naked, or hitting the caregiver so hard it broke her collarbone, to a litany of household mishaps and of what the care receiver could not or would not do (follow recipes, balance the checkbook, follow a storyline on a TV program, play cards, carry on a meaningful conversation, take a bath, change clothes). Often, previously familiar everyday occupations were carried out in an atypical manner by the care receivers, such as turning the thermostat “way up,” running the vacuum cleaner for hours at a time, repeatedly going over to the neighbors, or hiding things in the back of the cupboard.

The caregivers used the occupational successes and failures of the care receivers to describe the course of the disease. Early occupational signs of dementia often were recognized only in retrospect: “I remember now how he started to make some bad business decisions, and he scratched the new appliances during deliveries,” or “He drove on the wrong side of the road, and I knew something was wrong but I didn’t want to admit it.” One caregiver remembered one Christmas holiday when “there were gifts from my mother for everyone except my children . . . I thought my mother had done that out of spite, and I really blew my stack.” Months later, this son found a closet-full of wrapped gifts for his children in his mother’s house—long forgotten; “From that point on we were aware that there was something wrong with her, and that what I got mad at was just something she couldn’t help.”

The caregivers consistently used very temporal descriptors when describing the occupational state of the care receivers. Even examples of occupational well-being were couched in the language of temporariness: “We’re still getting along real well”; “He still goes to his poker group, but how long he’ll be able to play in that I don’t know”; “She can still do her volunteer work.” Monitoring for change in the care receiver’s status was evident. And for some caregivers, anticipation of much greater loss and impairment in the future was intense, including an eventual state of being “bedridden,” facing the need to institutionalize, seeing the caregiver “all curled up,” and fearing that the care receiver “will be incapacitated and lie there and not be able to do anything.”

**Theme 2: The Caregiver’s State of Being**

Just as the caregivers in the study used occupational terms to describe the care receivers’ states of being, so too did they describe their own well-being or lack of well-being in occupational ways. Narratives about themselves had to do with their general levels of ease and feelings of competence about the caregiving responsibilities and the sense of continuity or disruption in their lives associated with the illness contexts and their experiences.

**Well-being.** Moments of well-being for the care receivers were sources of satisfaction for the caregivers:

I think the one thing that my mother loved to do was to eat. When I would take her out to lunch at a cafeteria, for her to see the food there and for her to choose—that was not difficult; I mean she would take Jell-O and mashed potatoes and gravy, things that they do a great job of appealing to the Midwestern older woman, and then we could talk about the food, and that, maybe, was satisfying.

In the cafeteria situation described above, the food was on display, enabling this caregiver’s mother to see the possible entrees and to make choices successfully and independently about what to eat; further, the food gave the two of them something to talk about during the meal. The lunchtime outing of mother and daughter could be experienced in much the same way as it would have been before the dementia. For a little while, the presence of dementia did not dominate their lives, and the moment is remembered with some satisfaction by the caregiver.

In the main, the caregivers seemed to be able to derive satisfaction from their caregiving only indirectly. Incidents of a care receiver actually expressing appreciation, contentment, or comfort directly to a caregiver were rare in the data. When they occurred, the meaning of such incidents seemed especially potent:

The greatest thing I remember is, as I was leaving one evening, she came out to the driveway and said, “That was an awfully good dinner you fixed tonight, we should do that again sometime.” And I just felt kinda warm all the way home . . . that’s about as great as it comes.

**Lack of well-being.** The lack of such expressions of gratitude by the care receivers left many of the caregivers with only themselves to look to for judging situations and their own performance. Sometimes the caregivers’ assessments of their own competence were positive: “We’re still getting along real well”; “There’s nothing really that comes up that you can’t work around.” Alternatively, expressions of uncertainty and regret and a lack of belief in their own skills were pervasive in much of the interview data. These feelings seemed to be the source of lingering doubts, grieving, guilt, and anxiety—even for those whose care receivers were no longer living. One caregiver said, “I don’t think I ever felt satisfied with what I could do for her. I think that was a real sad part of my life . . . I was a very bad son at that point.”

The occupational experiences of the caregiving also represented at least two kinds of disruption in the caregivers’ taken-for-granted worlds: occupational disruption (a state of disrupted occupational engagement) and biographical disruption (a sense of discontinuity of self and one’s life...
course) (Becker, 1993; Kuyper & Wester, 1998; Whiteford, 2003). The following narrative from a wife caregiver reflects these disruptions:

At first I just thought he was getting forgetful, you know, like old age, but then I knew it wasn’t just forgetfulness. It got so I had to sit here 24 hours a day with him, I didn’t have any life of my own. I’d take him with me wherever I went, like if we went grocery shopping. That’s all we did, it was grocery shopping and go to church. That was for over a year. And then we’d come home and sit, that’s it. I didn’t go anywhere, I didn’t do anything, except look after him. It was plain hell, in two words—it was just practically like being in a prison.

And then he got so he didn’t know me. Now I know that because, one time, he was wiping the dishes for me, and he said, “What’s your name?” And I could see that, but yet I didn’t want to admit it. I just couldn’t accept it.

I’ve reconciled now that he’s gone [to a nursing home] and isn’t coming back. I cried probably the first 3 months. So, after that, I was kind of strange, and I didn’t want to talk to people; I had to get used to people. I’d say it took me about 6 months before I could go out and do things. I was broke up because he was gone.

Occupational disruption is painfully obvious in this caregiver’s description of her yearlong period of activity restricted to going to the grocery store or church and staying home. After her husband went to a nursing home, she “had to get used to people” again, and months passed before she was able once again to “go out and do things.” She said she felt “strange” after he left, and she was “broke up,” graphic metaphors for a sense of biographical disruption—a sense of strangeness and broken-ness instead of coherence in one’s life. The experience of her husband not knowing who she was is, perhaps, a quintessential experience of biographical disruption. His lack of recognition likely raises uncertainty about the essence of her own biography, so much of which has been shared with the care receiver in a spousal relationship. These kinds of disruptions led to the losses in her taken-for-granted world—the predictable world of daily experience previously taken for granted. It is not surprising that she could not admit or accept the reality of these changes right away.

For others, a sense of continuity in their lives was somehow maintained in spite of the dementia. One caregiver described how she resisted the attempts by the nursing home staff to get her to “let go” of her mother:

You’re told and you’re told, and I don’t know how many times I’ve been told in these 3 years, “This is not your mother anymore and don’t think of her.” But how do you turn that off? I can’t. I’m sorry. I cannot. That is still the woman that I remember as a child, and that I remember at my wedding, and that I remember at the death of my husband. She was there. And now, I’m not to consider her my mother?

Holding on to what remained of lifelong patterns often was tenuous, but as one wife caregiver said,

When we have had nice days, then he will be outside and work around the yard just like he always did. . . . We go to church on Sunday, which is something that we always have done. I guess just having him around—when you’ve been married to somebody for over 50 years, why, just being able to have him around is satisfying.

**Theme 3: The Search for Relationship**

Many of the everyday occupations described in the narratives appeared to represent efforts to ward off the potential “strangeness” of living with dementia. Caregivers developed occupational strategies to help hold onto whatever sense of relationship and remnants of “normalcy” remained in their daily lives—at home and in the larger community context.

Perhaps in particular, each caregiver struggled to maintain a semblance of connection and mutuality with his or her care receiver. Sometimes the sense of broken-ness prevailed, as when one daughter caregiver said, “It was like I didn’t have a mother anymore . . . she looked like my mother, but the words that were coming out and the things that were happening to her were not my mother.” For others, the sense of relationship and connection with the care receiver was actually strengthened in the dementia context. One son described taking his father for a ride in the car and having his father begin talking about “all the things he believed in . . . that was probably one of the most rewarding experiences I ever had with Dad, and it was while he had Alzheimer’s.” One husband caregiver said, “It’s satisfying that I can take care of her; that brings us closer together. I don’t think we’ve ever been as close as we are right now.” This caregiver’s efforts to maintain links with the past he had shared with his wife and to connect with her in the present were numerous and poignant:

We fight about showers. I put a mark on the calendar, and I keep reminding her; then after a couple days I have to insist. I’ll take her arm and lead her to the bathroom, and I’m firm about it. After the shower, I take her in my arms. Sometimes she’ll actually say “thank you.”

To be “together” for a moment in time seemed cherished and remembered.

A sense of reciprocity between caregiver and care receiver could be especially satisfying. To receive a hug after helping a care receiver get ready for bed, to hear the care receiver say “I love you,” or to have the care receiver take the caregiver’s hand while out on a walk—these incidents were spoken of as moments of great satisfaction by the caregivers. One caregiver said she missed the sense of being “taken care of” after the onset of her husband’s dementia. This caregiver had recently had surgery and she described her husband’s actions when she came home from the hospital:
I could see him trying to take care of me, and that made it a little easier to know that that person was still in there . . . just simple things that he could do like bring me blankets, bring me pillows, see if he could get me something like a glass of water.

Narratives about working with health professionals and the health care system revealed relationships that represented both mutuality and lack of mutuality. Staff members at a nursing home were referred to as “really helpful—if it weren’t for the staff, I don’t think I could make it.” Alternatively, other caregivers referred to their experiences with aspects of the health care system as “a nightmare,” like “being thrown on the garbage heap”; nursing home placement was “something I’ll regret all my life.” A lack of respect and understanding by health professionals was described:

When I took him up to the hospital for an X-ray, I was so sad for him that day because they didn’t get him re-dressed . . . and he forgot what he was there for . . . . Then he came back and said, “They didn’t like me,” and I said, “That’s okay, I love you, dear. We’ll put you together and we’ll go home and have breakfast, how does that sound?”

With few exceptions, caring for a person with dementia by these study participants seemed to lead to help from many other individuals in the public arena. In addition to assistance from the expected health care agencies, caregivers called on the police, the Alzheimer’s Association, neighbors, group home facilities, and the courts. Individuals specifically named by caregivers as helpers included the “mail lady,” banker, barber, security guard at a store (“they were so good, so gentle with her”), veterinarian (“the vet and I tried to keep that dog alive until mother died”), pastors and church friends, lawyers, and strangers in restaurants (“Virtual strangers would help take her to the restroom—I never got refused—I wouldn’t even have to ask”). One caregiver credited his involvement with Alcoholics Anonymous as being “one hell of a big help to me.” It seems that, overall, mutuality is a phenomenon that can be present and nurtured by the caregiver with a wide variety of people.

Discussion

In the narratives of caring for family members with dementia, everyday occupation emerged as a phenomenon that was central to the caregivers’ ways of evaluating and monitoring well-being in the care receivers and in themselves. In the daily worlds of many of the caregivers in this study, the fabric of well-being was, to borrow the words of poet Amy Clampitt (n.d.), “a broken, a much-mended thing.” For a few, the fabric did not seem “broken,” but it was, indeed, “much-mended.” The disruption of taken-for-granted patterns of engagement in daily occupation, competencies in everyday tasks of living, and long-established family and community relationships—brought on by the dementia—often led to wrenching challenges to the caregivers’ biographies and identities. As we have seen, however, these same disruptions also could lead to new patterns of engagement, the acquisition of different skills, and new attachments with family and community. Occupational strategies were a prime response by caregivers as they struggled to meet the challenges of living with dementia and create meaning anew in their changing lives.

The “March” of Dementia

On a general level, caregivers seemed to embrace the value of engagement in occupation, the same value that is such a strong core of the philosophy of occupational therapy (Rebeiro & Cook, 1999). For the care receiver to be engaged in everyday occupation with a modicum of success represented a “good.” Instances of success at carrying out even very simple everyday tasks were viewed as signs of relative well-being. In related research, others have used engagement in activity by persons with dementia as a quality-of-life measure (Albert et al., 1996) and a moderator of disturbing behaviors (Baum, 1995; Teri & Logsdon, 1991).

More specifically, the centrality of everyday occupation to the caregivers’ efforts to monitor the status of the care receivers’ well-being and trace the course of the dementia trajectory seemed evident. Changes over time in the care receivers’ performances in ordinary daily occupations emerged as strong embodiments of the dementia illness. Occupational changes were not merely regarded as signposts of the progression of the disease but also seemed to actually represent the disease itself; whereas occupational therapists frequently distinguish disease from disability, the caregivers in this study did not make this distinction. To no longer be able to crochet or to no longer be able to recognize your wife were not just symptoms of the disease, they were the disease.

Tracking competence in daily activities across time in dementia caregiving also is prominent in other research (Swenson, 2004; Vernooij-Dassen, Wester, Auf Den Kamp, & Huygen, 1998). The idea of illness as a socially constructed experience derived from one’s social context is certainly not new, although the concept has been largely explored in terms of people’s explanations of their own illnesses (Hunt, Jordan, & Irwin, 1989; Kleinman, 1988), or in the context of negotiation of meaning between patient and practitioner, and, sometimes, family member (Hasselskus, 1988, 1992b). Similar to the findings of Hunt and others (1989), the caregivers in the study reported here continued to “rework their illness understandings” as their ongoing life experiences unfolded (p. 955).
The concept of everyday occupation as a representation of dementia parallels the concept of illness representations proposed by Leventhal, Nerenz, and Steele (1984). For Leventhal and colleagues, illness representations occur when a person concludes that certain bodily sensations represent illness symptoms; at the point of reaching such a conclusion, the person gives the symptoms an illness label and begins to ideate about causes, consequences, and actions to be taken. We propose a parallel conclusion that as the caregiver observed changes in the care receiver’s performance of everyday occupation over time, he or she reached a point at which these changes were designated as illness, that is, Alzheimer’s disease. The caregivers’ reports of thinking that early occupational changes were just “old age” or just being “forgetful” are precursors to illness designations; illness labels were not given, causes and consequences were not thought about, and no action was taken until the frequency and perhaps scope of the changes led to an illness label. And at that point, the occupational changes observed by the caregivers became illness representations.

Incompetence in everyday occupation as an illness representation for Alzheimer’s disease implicitly includes the opposing concept—that continued involvement and success in everyday occupation is a wellness representation, or is at least an indication of relative well-being (Hasselkus, 1998; Kitwood & Bredin, 1992a). In this study, the family caregivers interpreted the well-being status of their care receivers by using many indicators of relative well-being, such as expressions of affection, humor, or pleasure and success in carrying out daily occupations.

In keeping with the concepts proposed by Kitwood and Bredin (1992b), the caregivers in this study believed that the observation of relative well-being in their care receivers somehow meant that they were providing good quality care, leading to feelings of satisfaction and their own sense of well-being. For them, the meaning of the everyday activities of the care receivers did not seem to be centered on whether or not they needed to provide assistance or whether or not they felt burdened, as has been the focus of much prior research on caregiving (e.g., see Kinney & Stephens, 1989; Pruchno, Burant, & Peters, 1997). Instead, to “still” be able to make choices in the cafeteria, to “still” be able to respond and smile at the grandchild, to “still” be able to enjoy going to a movie together—these everyday occupations had become special occasions to the caregivers. They indicated relative well-being in the care receivers, and they were sources of satisfaction and a sense of a job well done to the caregivers.

Shared Identities

Shared identity emerged as an overlying theme in the interpretation of the caregiver narratives in this study. In a symbolic interactionist framework, identities are part of the self, and, as such, are the outcomes of our lifetimes of symbolic communication with others in society (Goffman, 1967; Thoits & Virshup, 1997). Further, according to Stone (1962), identities are social locations; that is, they describe where one is situated in relation to others. As Charon (1992) said, “These identities become central to us over time as our interaction [in our social worlds] reconfirms them over and over” (p. 82). McAdams (1997) elaborated on the concept of multiple identities in modern life, and described such multiplicity as a “direct challenge to identity.” The challenge stems from the difficulties individuals experience in “integrating [multiple] self-conceptions into a pattern that suggests life unity and purpose” (p. 61).

The caregivers in this study provided their personal narratives of caring for family members with dementia, revealing the identity challenges of caregivers in this situation. Chronic illness is an accepted cause of disruption and change in people’s lives (Becker, 1994; Bury, 1982; Charmaz, 2002; Hoppes, 2005); for the caregiver–participants, the chronic illness was not their own, but we propose that its presence, nevertheless, caused disruption in their lives and forced major changes in their daily routines and ways of viewing their selves. The daughter caregiver’s statement that she felt as though she “didn’t have a mother anymore” can be seen as representing not only changes in her perceptions of her mother’s identity but also changes in how she regarded herself; the predictable mother–daughter patterns of interaction, reciprocity, and occupation of the past have been disrupted, as has that aspect of the caregiver’s biographical self that was embedded in the shared identity of daughter and mother. If this daughter caregiver doesn’t “have a mother anymore,” then what does that mean for who she is? What identities is she giving up, or continuing to possess but in new and different ways, and what new identities is she taking on?

Alexander and Wiley (1981) describe a phenomenon of situated activity, referring to conduct that takes place “from an orientation that includes particular others’ perspectives” (p. 273). In situated activity, “identity configurations emerge, accommodate new elements, and change over time” (p. 288). The care receiver with dementia is a particular other, and much of the caregiver’s conduct in daily life occurs within an orientation to the care receiver’s situation. The need for continuity of shared identities was evident in the data in several ways. As one example, a daughter appeared to be testing a new identity as a caregiver for her father as well as her mother:

I told my Dad about that support group because I think he needs one, but he hasn’t followed through on that. I’m going to tell him again. I’m also going to suggest hiring a...
nice neighbor girl to come in to be with Mom so Dad can get out. . . . I also think we should be putting Mom's name on a waiting list for a facility of some kind, but it's very upsetting to Dad to talk about it. And he refuses to sign for a power of attorney for her.

The daughter's considerable amount of situated activity provided conditions for the formation of a new emerging identity as caregiver for her father. This personal narrative illustrates her attempt to create unity and purpose in her life in the face of the challenge of her multiple identities. The daughter's situated identity of caregiver may not be shared by her father, hence the tug-of-war going on between them. These identity challenges likely contributed to tension among the family members.

Many of the incidents of caregiver satisfaction in the interviews are examples of the caregivers using everyday occupation to successfully maintain their shared identities with the care receivers. For the caregiver who experienced her husband trying to take care of her again after she had surgery, reminiscent of the ways he had taken care of her in the past, moments of familiar ways of relating to each other and of a familiar shared identity occurred. When her father enthusiastically “grabbed” the prime rib off the plate and started chewing it, the caregiver experienced a moment of sharing and familiarity in her continuing life together with her father. And to have her husband outside and working around the yard “just like he always did” and to go to church on Sunday, “something we always have done” represented moments of continued shared identity and satisfaction for another caregiver. In the words of McAdams (1990), such narrative episodes affirm “what the story maker sees as an identity ‘truth’ . . . what the person sees as an essential thread of continuity in his or her life story” (p. 169). Still being together and still engaging in long-standing shared identity occurred. When her father enthusiastically “grabbed” the prime rib off the plate and started chewing it, the caregiver experienced a moment of sharing and familiarity in her continuing life together with her father. And to have her husband outside and working around the yard “just like he always did” and to go to church on Sunday, “something we always have done” represented moments of continued shared identity and satisfaction for another caregiver. In the words of McAdams (1990), such narrative episodes affirm “what the story maker sees as an identity ‘truth’ . . . what the person sees as an essential thread of continuity in his or her life story” (p. 169). Still being together and still engaging in long-established patterns of occupation, however fleetingly, can offer support for a sense of unity and coherence and an “identity truth” for the caregiver of a family member with dementia.

Clinical Implications

The centrality of everyday occupation in the life experiences of caregivers for family members with dementia sends a strong message to occupational therapists: Everyday occupation holds promise for contributing to the relative well-being of both the caregiver and the care receiver. Further, everyday occupation potentially helps facilitate continuity of relationships and identities for the caregiver.

Successful engagement in everyday occupation by the care receivers was an important source of satisfaction to the caregivers in this study. Additionally, the caregivers often seemed to view the care receivers’ success in daily activities as a sign that they (the caregivers) were providing good care. As we work with people with dementia and their families, we may enhance caregiver satisfaction by recognizing this affirming aspect of a client’s everyday occupational performance and by working to maximize occupational success through adaptation and simplification. Helping the caregiver who is deeply dissatisfied with his or her experience to recognize moments of success can potentially lift his or her spirits and sense of effectiveness. Perhaps in the future we can help prevent caregivers from looking back on their experiences as a “real sad part” of their lives or as a time when they were “bad.”

Especially pleasing to the caregivers were incidents when the care receivers engaged in occupations that were like what they did “before” the onset of the dementia. We have interpreted the satisfaction experienced in these moments to be related to the caregivers’ need for maintaining long-standing shared identities while also meeting the challenge of adapting to new identities. Understanding the identity challenges embedded in the caregiving context and the important role of occupation in meeting some of those challenges suggests interpretations of successful occupational performance beyond the traditional concepts of independence and autonomy for the care receiver. Rather, everyday occupation is viewed as an integral part of one’s personal and shared identities. Engagement in occupation becomes recognized as a vital component of the expression of who one is. For the caregiver of a family member with dementia, occupation becomes a unique symbol of biographical and social identity (“He always loved prime rib”) and an enabler of continuing moments of unity and purpose in one’s life. Although Orono (1990) referred to such moments as memory keeping, we might refer to them as identity keeping.

A final compelling example of the use of occupation in relationships appears in the narratives in the form of an ordinary household appliance used in the home—the vacuum cleaner. One caregiver described how his mother would “run a vacuum cleaner for 8 hours”; his response to her vacuuming was to “take it away from her because she keeps burning my vacuum cleaners out.” In contrast, another caregiver pleaded with the repairman to keep the vacuum cleaner working so his wife could continue to run it and would not have to try to learn how to use a new and different one. The sense of emotional connection between the latter caregiver and care receiver is palpable. Perhaps the first caregiver could be guided to help make decisions about how to support patterns of everyday occupation that best accommodate the needs of the care receiver when possible.

The narratives sustain beliefs about the potentially positive contributions of family and community relationships to a caregiver’s life, in contrast to caregiving alone. The caregiver who voiced her difficult experience of feeling
“broke up” and “strange” after her husband went to a nursing home was the one who lived through months of sitting at home with her husband and described that period of her life as like “being in a prison.” Other people can obviously offer physical help with the care tasks, but they also are a potential source of support and validation to the caregivers’ efforts. Given the suggestion in these data that the care receiver rarely provides such feedback directly to the caregiver, having other sources for a pat on the back or an expression of gratitude seems important. Being sensitive to the probable paucity of validation in the caregiver’s life can enhance therapeutic relationships in this context and support caregivers’ sense of worth, effectiveness, and self-confidence.

Conclusions

Although we did not use the word occupation in the key interview question itself, thus not leading the study respondents directly into discourse about occupation, we did purposely seek occupation-related data from the interviews for this analysis. Occupation, however, was so overwhelmingly present in the interview transcripts that the interpretations reported here seem well grounded and authentic. We would argue that everyday occupation often is present but marginalized in research analyses because it is a part of our everyday, taken-for-granted worlds; as occupational therapy personnel, we are one exception to this general tendency to ignore what is, in reality, such an important part of our lives. We see and value what is invisible to others. To us, the presence and importance of everyday occupation in the experiences of these family caregivers seems clear—as they sought to maintain well-being for their care receivers and themselves, as they struggled to understand changing relationships and to establish new ones, and as they responded to the demand for changes in their identities.

The concept of well-being derived from the occupational competence of an “other,” as was the case for the caregivers in this study, deserves further study in this and other contexts. Is occupational competence of a child with a disability, as promoted in therapy, linked to the well-being of a parent? Is the occupational competence of a person recovering after having had a stroke related to the well-being of his or her partner? If so, what is the nature of that relationship? Under what circumstances is the relationship present?

The need for family caregivers to receive validation of the quality of the care they are providing from sources other than the care receiver seems an important new understanding from these data. Because the patterns of interaction that typically include the social niceties of saying thank you, showing affection, or reciprocal helping are often absent for the person with dementia, how can we help the caregiver find other ways to validate his or her care? Additionally, what ethical dilemmas in dementia caregiving arise from occupational situations (“I took the vacuum cleaner away from her”), and how can we assist caregivers to make everyday ethical decisions? And finally, we need to seek better understanding of the social and cultural dynamics of caring for a family member with dementia and the relationship of a potentially wide-ranging array of support to the well-being of the caregiver and care receiver. ▲

Acknowledgments

This research was supported by the Helen and Philip Brody Pilot Research Grant from the Alzheimer’s Association, Inc. The authors thank Susan A. Rosa, PhD, for her assistance with the interviews and early data analysis.

References


The American Journal of Occupational Therapy 19


---

We’re striving to make *AJOT* the “go-to” journal for information about evidence-based occupational therapy, and that takes everyone’s involvement.

*How are you contributing? Be a reviewer!*

Occupational therapy is a diverse field, and we need reviewers in many traditional and emerging areas. If you are a seasoned researcher, emerging scholar, or experienced practitioner, consider joining the AOTA review board. It’s a rewarding form of professional service that gives back as much as it requires. Interested in publishing in *AJOT*? One of the best ways to improve your own writing is by critiquing other manuscripts.

We particularly need reviewers in the following content areas:

- Instrument validation
- Physical rehabilitation
- Statistical analysis
- Occupational therapy education

If you are interested in being a member of the *AJOT* Editorial Board, send your résumé or CV to the Editor (ajoteditor@cox.net). Each member serves a 3-year term and reviews between 3 and 6 manuscripts per year, depending on his or her area of expertise.